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The Commonwealth of Massachusetts
EXECUTIVE DEPARTMENT OFFICE ON DISABILITY
Progress Report 1995-1999

Argeo Paul Cellucci, Governor
Jane Swift, Lieutenant Governor
Lorraine Greiff, Acting Director

[Privacy Statement](#)

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II. INTRODUCTION:

Letter from the Director

Dear Colleagues:

The Massachusetts Office on Disability (MOD) Progress Report covers fiscal years 1995 through 1999. It provides information about the agency's history, organizational structure, and the scope of services we provide, as well as highlights of recent accomplishments. These are exciting and challenging times for people with disabilities, their families, friends and advocates. In the last two decades many institutions have closed and individuals have moved into the community. For many, the American ideals of independence, self-determination, and autonomy, are becoming realities. But, too many hurdles still exist. In its capacity as the state advocacy agency for people with disabilities, the Office on Disability plays a vital role in helping people achieve their ideals. It serves as ombudsman, conscience, facilitator, and critic as major changes in state policies and services emerge, and resources are redirected to provide community supports, access, accommodations, and opportunities. While MOD is a small agency with very limited resources, its output is significant. Each year we see an increase in the number of requests for assistance, both in dealing with the state service system and access to the community. These requests come from consumers, other state and local agencies, friends, and family members. The work of our agency is based on a vision of a barrier-free world in which there is no discrimination against people with disabilities, and the dreams of owning one's home, meaningful employment, and social integration have come to fruition. The Commonwealth of Massachusetts provides many opportunities in that direction. We hope you enjoy reading this report and learning about the activities that take us down the road to that ultimate destiny. Should you like more information about MOD, the staff, and I welcome your inquiries.

Sincerely, Lorraine Greiff, Acting Director

Photo: Lorraine Greiff

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III PROFILE OF PEOPLE WITH DISABILITIES

December 1999

WHO ARE PEOPLE WITH DISABILITIES?

They are 19 percent of the population and include all ages, based on the latest census statistics. Applied to Massachusetts, this means that there are approximately 1,150,000 individuals with disabilities. More than 390,000 are between 65 and 74 years old, and approximately 274,000 are over 75. Six percent of people with disabilities in Massachusetts (70,000) are under 15 years of age and fifty-nine percent are working age; in that group 52% are men and 48%, women. More

women than men have a disability in the 65+ age group and the ratio increases with age. Among children less than 15 years old, more boys (7.2%) than girls (4.4%) have a disability.

The fastest population growth rate is in the 85+ age group. In Massachusetts in 1992, a total of 95,000 people, or 1.5% of the population, was over 85 years of age; about 50% have substantial disabilities. Between 1990 and 2000 the over 85 population is expected to grow by 39.1%. In the next decade, 2000 - 2010, 21.1% of the population will be over 85.

Approximately 12% of individuals with disabilities are of minority status. African Americans represent 5%, 4.8% are Hispanic, 2 percent are Asian American, .2 percent are American Indian, Eskimo, or Aleut. About 2% fall into the "other" category. The incidence of disability is higher among African Americans (21%) in the 15 to 64 year range than it is for Whites (18%), but the ratio reverses after 65 (Whites 13% and African Americans 9%). Eighteen percent of people with disabilities are functionally limited which means they have trouble climbing stairs, walking three city blocks or lifting a full bag of groceries; five percent have difficulty reading ordinary newsprint and 6% have difficulty hearing what is said in an ordinary conversation. Eight percent have difficulty getting out of bed, dressing, eating or taking a shower while 12% of people with disabilities have difficulty preparing meals or doing light housework.

Among disabling conditions which prevent individuals from working are arthritis and rheumatism (17%), back or spine impairment (14%), heart, including arteriosclerosis (11%), high blood pressure (5%), respiratory trouble ((7%), mental illness (2%), and mental retardation 1.2%).

SOCIO-ECONOMICS

At the end of 1996 (December), a monthly average of 115,000 disabled Massachusetts workers, 4300 spouses, and 34,530 children of those workers, received Social Security Disability

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Insurance (SSDI); the benefits totaled \$87 million (federal dollars) for that month. The average monthly benefit received is \$697.00. Footnote 1: "STATE STATISTICS", Massachusetts, Social Security Administration, Office of Research, Evaluation and Statistics, December 1996. End Footnote 1. The program is funded through payroll taxes (FICA) consisting of equal contributions from employer and employee. Eligibility is based on one's work history during which s/he contributed to the Social Security program through FICA, and a disabling condition that precludes a person from working for a year or more. Spouses and children of individuals who receive benefits are, in some cases, also eligible.

That same month 114,450 individuals with disabilities and 4,511 people who are blind received a total of \$49.6 million (an average monthly payment of \$417) from the Supplemental Security Income (SSI) Program which is funded by a combination of state and federal dollars. Footnote 2 Ibid. End Footnote 2. Eligibility for this program is based on financial need and one's living situation - i.e. whether one lives alone or shares housing. In most cases, the person who lives alone would receive a higher monthly benefit.

The income gap between adults with disabilities and non-disabled adults has increased from 16% to 22 % since 1986. Currently 34% of adults with disabilities live in households with total

incomes less than \$15,000, versus 12% of nondisabled individuals. Footnote 3: 1998 National Organization on Disability/Louis Harris & Associates Survey of Americans with Disabilities, Press Release of Executive Summary Survey Findings July 27, 1998. End Footnote 3.

EMPLOYMENT

A 1998 survey conducted by Louis Harris for the National Organization on Disability revealed that 71% of working age (i.e. 18 - 64) individuals with disabilities are unemployed. The survey also determined that the vast majority of people want to work. This number has not improved since 1986. In contrast, the unemployment rate for people who do not have a disability is approximately 20%. Footnote 4: Ibid. End Footnote 4. Furthermore, only 20% of disabled individuals who are working have full time jobs. Among people with disabilities who are employed, 16% are in professional or managerial positions, or proprietorships, 14% are service workers, 13% are in sales or hold clerical positions, 12% are unskilled laborers or farmers, and 7% are skilled craftspeople. Footnote 5: "N. O. D. Survey of Americans with disabilities, Employment-Related Highlights", by Humphrey Taylor, president and CEO, Louis Harris and Associates, Inc. In "Business Week", May 30, 1994. End Footnote 5.

Within the group of people who have a severe disability there is little difference in the number of men vs. women who have jobs. There is a significant correlation between the number of
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functional limitations, their severity and employment. These statistics indicate a number of job-related barriers for people with disabilities. Job-related barriers include lack of education or skills training, need for transportation to the work place, inaccessible work sites, and the need for help with self-care at home and work.

EDUCATION

Since 1972, children with disabilities in Massachusetts have been entitled to a free and appropriate education under Chapter 766, a comprehensive special education law. A 1998 Harris poll indicates the number of adults with disabilities who have a high school diploma has risen since 1986 from 60% to 80% and the number of those with some college education has risen from 29% to 44%. Footnote 6: "Protection & Advocacy Systems News", National Association of Protection & Advocacy Systems, Vol.1 Issue 2, August 1996. End Footnote.

In Massachusetts, 159,042 (16.6%) of the total public School enrollment received special education services in in Fiscal Year 1998 (1997 - 1998 school year). Footnote 7: Numbers pertaining to special education students are based on students 3 - 21 years of age versus numbers pertaining to students in regular education in public schools which are based on students aged 5 - 18. End Footnote. Approximately 100,000 of the total number of students in special education are in inclusive classrooms (they spend no more than 25% of their education time out of the classroom in order to receive special education services). Of this population, 1% receive education services in residential, home, or hospital school programs.

Chapter 688, enacted in 1983, provides a two year transitional process for severely disabled young adults who continue to need supports when they either graduate from high school or reach their 22nd birthday and Chapter 766 services end. In Massachusetts approximately 1026 new students were referred to this program by their local school district in Fiscal Year 1998.

Footnote 8: "Chapter 688" Turning 22" Program, A Report to the Legislature", Executive Office of Health & Human Services, William D. O'Leary, Secretary, October 30, 1997, Figure 2, pg. 6. End Footnote. Currently (FY'99) 5,595 students participate in transitional programs.

SOURCES

Americans With Disabilities: 1991-92, Data From the Survey of Income and Program Participation by John M. McNeil, U. S. Dept. of Commerce, Economics and Statistics Administration, Bureau of the Census.

“1990 Census of Population, Social and Economic Characteristics, Massachusetts”. Issued September 1993, U. S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census.

“N.O.D. Survey of Americans with Disabilities, Employment-Related Highlights: By Humphrey Taylor, President and CEO, Louis Harris and Associates, Inc., in “Business Week”/ May 30, 1994.

“1998 National Organization on Disability/Louis Harris & Associates Survey of Americans with Disabilities”.

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“Infrastructure Of Home and Community Based Services For The Functionally Impaired Elderly”, State Source Book, Administration on Aging, U. S. Department of Health and Human Services.

“STATE STATISTICS”, Massachusetts Social Security Administration, Office of Research, Evaluation and Statistics”.

“Protection & Advocacy Systems News”, National Association of Protection and Advocacy Systems”.

“Chapter 688 “Turning 22” Program, A Report to the Legislature”, Executive Office of Health & Human Services, William D. O’Leary, Secretary, October 30, 1997.

WEB SITES

<http://www.ssa.gov>

<http://www.census.gov>

<http://www.nod.org>

IV AGENCY HISTORY

The Massachusetts Office on Disability (MOD) was created in 1981 under Chapter 6, Section 185 of the Massachusetts General Laws. By 1985 it was fully staffed and functioning.

MOD is an independent state agency whose mission is to “bring about full and equal participation in all aspects of life by all persons with disabilities in the Commonwealth”. Its statutory mandate extends to two broad areas: (1) advancement of the legal rights of individuals

with disabilities; and (2) promotion of the maximum possible opportunities, support services, accommodations, and accessibility for individuals with disabilities.

Its priorities are:

1. The elimination of discrimination against people with disabilities
2. The goal of a barrier free environment
3. The improvement of the delivery of state services to those who need them
4. The guarantee of accessible housing, transportation, and equal job opportunities in the public and private sectors
5. The promotion of awareness pertaining to the needs of people with disabilities.

Photo of Executive Staff members Myra Berloff, Lorraine Greiff, Penny Goerlach, Barbara Lybarger and Michael Dumont.

The Office has three main components that function to fulfill its priorities: the Client Services Program, the Community Services Program, and the Government Services program. While each program is uniquely distinct, they intersect and interact with each other in order to effectively ensure that people with disabilities are treated fairly in the Commonwealth.

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**Massachusetts Office On Disability
Organizational Chart, September 24, 1999**

DIRECTOR

Lorraine Greiff Acting

BUSINESS MANAGER

Michael Dumont

RECEPTIONIST

Amy Ranji

SPECIAL PROJECTS

Penny Goerlach Assistant Director

COMMUNITY SERVICES

Myra Berloff Assistant Director

CLIENT SERVICES

Assistant Director

And

GENERAL COUNSEL

Barbara E. Lybarger

UNIT CLERK

James Wilcox 03
ADMINISTRATIVE SUPERVISOR
Christopher Coyle
ADVOCATE
Naomi Goldberg
CIVIL RIGHTS ADVOCATE
Phyllis Mitchell
CAP ADVOCATE
Brad Pearson
CAP ADVOCATE
Max Ibanez
CAP ADVOCATE
Mary Fitzgerald

COMMUNITY SERVICES
ASSISTANT DIRECTOR
Myra Berloff
COMMUNITY SERVICES COORDINATOR
Peter Pomponi
ACCESS SPECIALIST
Ralph Hickey 03
COMMUNITY ACCESS MONITOR PROGRAM
COORDINATOR
Bruce Bruneau

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Agency Budget

Since FY89 MOD's budget has gradually been reduced approximately \$100,000. \$50,000 of MOD's annual appropriation is really a set aside for Very Special Arts (VSA), a program for children with disabilities. MOD is just a conduit for Very Special Arts funding.

At the same time, MOD's responsibilities have significantly increased. Since passage of the Americans with Disabilities Act (ADA) in July 1990, the Office on Disability has been the designated agency for ensuring compliance with this law. MOD is also responsible for the administration and coordination of the Inter-Agency Disability Services Coordinating Council and the Governor's Advisory Commission on Disability Policy. Both bodies make recommendations to the Governor to improve the disability service system.

Photo: Amy Ranji, Receptionist

Listed below is the Massachusetts Office on Disability's appropriation history since State Fiscal Year 89:

Fiscal Year	Total Appropriation	MOD Appropriation	VSA
FY89	\$ 692,964	\$692,964	—

FY90	\$ 605,294	\$ 605,294	—
FY91	\$ 499,344	\$ 499,344	—
FY92	\$ 564,210	\$ 514,210	\$50,000
FY93	\$ 515,753	\$ 515,753	—
FY94	\$ 527,341	\$ 447,341	\$50,000
FY95	\$ 536,879	\$ 486,879	\$50,000
FY96	\$ 525,246	\$ 475,246	\$50,000
FY97	\$ 540,392	\$ 490,392	\$50,000
FY98	\$ 616,213	\$ 566,213	\$50,000
FY99	\$ 643,158	\$ 593,158	\$50,000

1. The total appropriation column indicates the amount shown in MOD's budget line item 1107-2400.
2. Please note that yearly increases shown above are Cost of Living only.

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V. PROGRAMS

COMMUNITY SERVICES PROGRAM

The Community Services Program consisting of 2.5 people and a clerk, interacts with about 10,000 people a year. It assists them in learning about the rights and responsibilities of people with disabilities.

Through training and technical assistance, it helps ensure that state and local entities, as well as places of public accommodation, know how to comply with their non-discrimination responsibilities. The Program conducted approximately 75 trainings in the past fiscal year, and an additional 5,000 people were provided technical assistance on accessibility by phone.

Photo: Community access survey in process

Primary Mission/Functions Currently Served

- To ensure the civil rights of people with disabilities and to empower them
- through knowledge to ensure full and equal participation in all aspects of life
- To foster the creation of and provide guidance and technical assistance to Commissions on Disability throughout the Commonwealth. There are about 190 such entities.
- To provide statewide Community Access Monitor trainings to people with disabilities, municipal employees, building inspectors and others
- To educate Commonwealth, municipalities, profit and not-for-profit agencies and citizens throughout the Commonwealth on the requirements of the ADA
- To create and distribute disability rights related information materials.

Community Access Monitor (CAM) Program

The Community Access Monitor (CAM) program is an essential component of the Community Services Program. Through the CAM program, MOD has trained thousands of people about state

access laws, the Americans with Disabilities Act, and other pertinent state and federal laws. This has resulted in 1,000 certified volunteer monitors who work with us in their communities to assure physical and communication access.

Examples of Frequently Asked Questions in the CAM Program

1. Does the Americans with Disabilities Act require all municipal and state buildings to be accessible?

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Not exactly. The ADA requires all municipal and state programs, services, and activities to be accessible. Sometimes that requires structural changes to a facility; but sometimes programs can be made accessible through reassigning people or programs to accessible sites, providing home visits, or other programmatic means. Newly constructed facilities and new renovations must be accessible.

Photo: Community Services Staff Myra Berloff, Bruce Bruneau, Ralph Hickey and James Dougan

2. What about other buildings that are open to the public, such as stores and restaurants?

Existing facilities, including stores, restaurants, and other public accommodations, must make any access improvements that are “readily achievable” (easily accomplishable and able to be carried out without much difficulty or expense). Newly constructed and renovated facilities must be accessible.

3. If a store has a “no animals” policy, are they required to let in people with guide dogs?

Yes. A general “no animals” policy is an example of a policy that discriminates against people with disabilities, which should be modified to allow people with disabilities who use service animals to use the store.

4. Which should be used if the state and federal design guidelines differ?

If the state and federal standards differ on a particular requirement, always use the more stringent one (i.e., the one that provides the greater degree of access).

5. What laws apply to federal agencies and facilities, such as post offices?

Section 501 and 504 of the federal Rehabilitation Act of 1973 and the Architectural Barriers Act of 1968 cover all federal facilities. They are not covered under the ADA or the AAB.

Municipal Access Survey

In 1995, five years after the Americans with Disabilities Act (ADA) was signed into law, MOD’s Community Services Unit conducted a prodigious survey of the 351 municipalities in the Commonwealth. The survey’s purpose was to determine whether the ADA had made a difference in access to facilities and services in cities and towns. Results were compared to the

Community Services Unit's municipal access

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survey, which had been conducted in 1988, 2 years prior to the ADA. The survey consisted of questions regarding general ADA implementation requirements as well as questions regarding access to town buildings and meetings. A follow-up survey is planned for 2000.

Polling Place Access Project

A cooperative effort is underway to assure that all polling places in the Commonwealth are fully handicapped accessible. The Massachusetts Office on Disability (MOD), volunteers from its Community Access Monitor (CAM) Program, along with the Office of Secretary of State and the city and town Clerks have embarked on this ambitious project to survey each of the state's 1200 polling places.

Photo: Community Services Staff and Lorraine Greiff meet with U.S. Attorney General Janet Reno

Both State and Federal law require polling places to be accessible. Yet, almost 15 years after the Federal Voting Accessibility for the Elderly and Handicapped Act took effect, voting for some people with disabilities is still problematic. Some of the access barriers pertaining to polling places include lack of handicapped parking, poor lighting, unmarked (and sometimes locked) accessible entrances, and lack of accessible voting booths. Trainings on polling place access are being conducted by MOD and the Election's Division of the Secretary of State.

VSA Arts

As a direct result of the Community Access Monitor Program, a unique national initiative, the Cultural Access Institute, has been developed between Very Special Arts of Massachusetts, with its strong ties to the cultural world, and the Massachusetts Office on Disability, with its ties to the disability advocacy world. For each of the past three years, teams of three people from 8 different states have come to the Institute to learn how to cooperatively make changes that ensure the equal participation of people with disabilities in all aspects of their lives, but particularly in cultural programs. As of 1999, 25 states have come to Massachusetts to receive training in disability rights, awareness, and advocacy. In 1999, eight members of the Salt Lake

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Olympic Organizing Committee Winter Games 2000 also participated in the training.

Disability and Technical Assistance Center (DBTAC)

The New England Disability and Technical Assistance Center is one of ten Centers (DBTACs) across the country which is funded by the National Institute on Disability Rehabilitation and Research, a division of the federal Department of Education. MOD is the Massachusetts affiliate of DBTAC, and receives a small grant to provide education and technical assistance to facilitate voluntary compliance with, and effective implementation of the Americans with Disabilities Act (ADA). Any individual, municipality, or business may request technical assistance on the rights of people with disabilities and the responsibilities of various entities to ensure non discrimination in their policies and practices as defined by the ADA.

Commissions on Disability

One of the ways MOD fulfills its mission is by working closely with local Commissions on Disabilities. The Commissions are formally established by a vote at Town Meeting or by City Councils. The majority of their members, all of whom are appointed by selectmen, mayors, or city managers, must be people with disabilities. One immediate family member may also serve on the Commission and there must be an elected or appointed official.

Photo: Community Services Clerk, Peter Pomponi

The Commissions work in their communities to promote inclusion and integration of people with disabilities in all activities, programs, services and employment opportunities. There are approximately 190 Commissions in the Commonwealth. The Office on Disability provides technical assistance on how to become formally established, and on the laws and regulations that ensure the civil rights of people with disabilities in their communities, as well as advice on implementing them. It also provides Commissions with information and referrals, technical assistance to individual members, and assistance with advocacy and education of the public on disability issues. The statute, G. L. c. 40 §8J, that created Commissions also advises them to work in coordination with MOD.

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Examples of Cases from the Community Services Unit

Case Number 1:

In December, 1998, The U. S. Attorney's Office called the Massachusetts Office on Disability (MOD) requesting assistance. It had received a number of complaints regarding access into businesses on the island of Nantucket. Its investigators had been sent to the island and had ultimately cited 85 businesses as being out of compliance with the ADA. It then sent letters to these businesses requesting them to develop plans for removing architectural barriers. The US Attorney's Office was aware that Massachusetts has state regulations regarding access and wanted to ensure that the business owners were receiving complete, accurate information. It asked MOD to participate with them in providing training and technical assistance on the access requirements of the Americans with Disabilities Act (ADA) and the State Access Code. MOD sent representatives to Nantucket to conduct trainings with them for contractors, architects, business owners, the Chamber of Commerce, and other interested parties.

Typically the Community Services Unit does not work with individual clients. It does, however, get certain cases that at first appear to be systemic (and ultimately benefit the community as a whole), but in the short term benefit specific individuals.

Case Number 2:

A student who uses a wheelchair was unable to enter the school building independently. She was not able to participate in a number of classes because they were located on the second floor and

there was no elevator. She was not able to participate with other students at events held in the auditorium or gymnasium, and she was not able to use a bathroom with privacy because the stall space was too small to allow the door to close. The family requested that we visit the school, survey the building to determine what barriers existed and to help develop a plan to ensure this student would be able to participate in all school activities. After a number of visits many of the barriers were removed. The ramp was fixed, the bathroom stall was widened, and grab bars were properly installed by the toilet. Access was provided to the auditorium and the gym, and a plan was developed to move the classes that were on the second floor to the first in order for her to participate with her classmates.

Case Number 3:

A Commission on Disability had been unsuccessful in working with its local community businesses to remove “readily achievable” architectural barriers. The Commission called the Office on Disability and asked for assistance in learning more about tax breaks and low cost ways of removing architectural barriers. MOD provided that assistance, and subsequently the Commission has been very successful in making their community more useable for everyone.

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Case Number 4:

For years a town had used a historical building as their local polling place, but this presented an access problem for people with disabilities. The polling place was up a set of steep stairs, so anyone who was unable to climb them had to vote in a separate place or at curbside. The local Commission on Disability asked MOD to assist in making the building accessible so that everybody could vote together. The Office helped the Commission and a way was found to move the polling booths downstairs. Now everyone can vote in the same place. As a result, the tradition of voting in the historical building continues.

Case Number 5:

A Commission on Disability asked for assistance when it noticed that new sidewalk construction appeared to lack curb cuts. MOD confirmed that the local Department of Public Works had planned on omitting the essential curb cuts. MOD worked successfully with the town. The Commission was included in the project, and consequently such a mistake will hopefully be avoided in the future.

Case Number 6:

A new hotel was inaccessible. Its architectural dimensions were wrong – i.e. parking spaces were too small and the only access to the front door was through a revolving door. The accessible entrance was not only too heavy, but it was also kept locked and blocked by plants. The public rest rooms did not have enough space in their entryway to accommodate wheelchairs and there was not enough space next to the toilet in the accessible bathroom for a wheelchair. The telephones had no volume control and there were no TTYs (telecommunication devices for the deaf, hard of hearing and people with speech impairments). There were also not enough handicap guestrooms and those they did have were not properly accessible.

MOD was asked to work with the hotel owner to provide technical assistance and education regarding compliance with ADA access requirements. As a result, the new hotel was altered to

be accessible as well as the other hotels in their chain.

Case Number 7:

A municipality's town hall was inaccessible. There were no handicap parking spaces in its parking lot and no curb cuts, which would allow people with disabilities to get to the town hall. The building had a ramp, but it was too steep to be used by a person with a disability and led to the fire door, which not only had no outside hardware, but also was kept locked. Inside, only first floor services were accessible, but all meetings were held on the second floor and there was no vertical access. There was also no TTY. The Office on Disability was asked to educate the municipality on how these factors discriminated against people with disabilities.

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CLIENT SERVICES PROGRAM

The Client Services Program provides information and referral services to people with disabilities, their families and friends, as well as to other interested people. It is the central source for reliable information concerning exactly what services are provided by what agency and under what eligibility rules. A part of MOD's activities since 1984, the Client Services Program (CSP) centers on a federal grant from the U. S Department of Education's Rehabilitation Services Administration (RSA). receives for the CAP to create a full service advocacy system for people with disabilities in Massachusetts. It assists people in finding the services they need and to which they are entitled. If these services are denied, Client Services assists by advocating for the individual. It serves people of all ages and disabilities and is a free, confidential service. Over the past three years, Client Services has seen a 33% increase in demand for services.

Photo: Client Services Staff James Wilcox, Naomi Goldberg, Mary Fitzgerald, Brad Pearson Barbara Lybarger and Phyllis Mitchell

A staff of six advocates delivers the following services:

1. Information and referral services concerning rights of and services to people with disabilities, their families, friends and support personnel; to federal, state and local officials, and to businesses and to other interested parties.

2. Administrative advocacy services for individuals with disabilities who are experiencing difficulties in the following areas:

- a. obtaining government services to which they are entitled,
- b. violation of their disability related civil rights, and
- c. obtaining vocational rehabilitation and/or independent living services funded in part by the Rehabilitation Services Administration (RSA) and administered by the Commonwealth.

In order for the Commonwealth to be eligible for in excess of \$40 million in federal funds for

vocational rehabilitation (VR) and independent living (IL) services, it must maintain a “Client Assistance Program”(CAP) independent from the VR agencies to provide information and referral and advocacy services for individuals who are having difficulties in obtaining those services. Using its state appropriation, MOD has augmented the federal funds it

The advocacy MOD provides resolves numerous complaints quickly and informally. In addition to

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resolving individual problems, MOD uses the experience gained in working with people with disabilities to identify those areas of Massachusetts law and practices which actually, rather than theoretically, cause unnecessary difficulties. Analysis of types of problems reported and the resolutions obtained provides the Commonwealth with a reliable, unbiased source of information about what the real barriers are that people with disabilities face.

Client Services Program Requests

Table 1: Totals Client Services Requests By Fiscal Year

1995	4,452
1996	5,447
1997	5,019
1998	5,734
1999	6,552

In Fiscal 1995, the Client Services Program received 4,452 requests for assistance from consumers, government officials, businesses and the general public. By 1999, requests had increased by 47%, to 6,552 requests. See Table 1, above.

Those requests were handled by a staff of 5.8 people in 1995. Current staff includes six people. The staff to request ratio was one staff member to 767 requests in 1995. In 1999, the ratio had increased to one staff member to 1,088 requests, a 42% increase.

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Requests by Category

Requests for assistance are grouped into eight broad categories:

Americans with Disabilities Act, Abuse and Miscellaneous Individual Rights Issues, such as public accommodations, service animals and voting
Education,
Employment,
Government Benefits,
Health Care,
Housing,
Other requests, including but not limited to equipment, insurance, legal assistance, taxes and utilities,

Personal Care and Independent Living,
Transportation, including automobiles, parking, mass-transit and all other transportation, and
Vocational Rehabilitation.
Footnote: Americans with Disabilities Act and Access requests do not include requests received
by the Community Services Program and others. End Footnote.

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Table 2:

In the ADA, Abuse and Individual Rights category, requests were 528, declined to 400 in 1996 and then rose steadily throughout the rest of the period, ending at 522. Education related requests ranged from 146 in 1995 to 212 in 1999, a 45% increase. Concerns about employment rose by 53% from 554 in 1995 to 846 in 1999. Despite low 1995 volume at 488 requests, Government Benefits call end up 66% at 808 in 1999. Health Care concerns ranged from a low of 249 in 1995 to a high of 435 during the PCA crisis of 1996 and 409 in 1997, ending the period with a 72% increase at 429. Showing the most substantial increase over the period, housing requests increased 75% over this five year period, beginning at 569 in 1995 and ending at 998 in 1999. Despite a one year decline in 1997, all other request rose by 33% from 874 to 1,172. Personal Care and Independent Living requests more than doubled during the period, moving from 150 in 1995 to 311 in 1999. Transportation related requests rose slightly throughout the period, ranging from a low of 338 in 1997 to a high of 409 in 1999 or 21%. Vocational Rehabilitation requests rose from 556 in 1995 to 845 in 1999, for an overall gain of 52%.

Footnote: Percentages may not total 100% due to rounding. End Footnote.

Photos: Phyllis Mitchell and her guide dog, Sage. Client Services Administrative Supervisor Christopher Coyle Retrieves materials for a client.

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Table 3: Client Services Requests by Category for 1995 (a pie chart)

The three most common categories of requests in 1995 were Housing 569 (13%), 2 Vocational Rehabilitation 556 (12%), and Employment 554 (12%). Those were followed by ADA, Abuse and Individual Rights 528 (12%), Government Benefits 488 (11%), Transportation 338 (8%), Health 249 (6%), Personal Care and Independent Living 150 (3%) and Education 146 (3%). There were 874 (20%) Other requests.

Footnote 3: For 1995, the Other Category includes Equipment 116 (3%), Insurance 35 (0.7%), Legal Assistance 142 (3%), Miscellaneous 510 (11%), Recreation 6 (0.013%), Taxes 17 (0.38%), Utilities 48 (1%). End Footnote.

Table 4:

The three most common categories of requests in 1996 were Housing 855 (16%), Vocational Rehabilitation 802 (15%), and Employment 683 (13%). Those were followed by Government Benefits 634 (12%), Health 435 (8%), ADA, Abuse and Individual Rights 400 (7%), Transportation 379 (7%), Personal Care and Independent Living 240 (4%) and Education 183 (3%). There were 836 (15%) Other requests. Footnote 4: For 1996, the Other Category includes Equipment 101 (2%), Insurance 22 (0.4%), Legal Assistance 208 (4%), Miscellaneous 424 (8%), Recreation 2 (0.004%), Taxes 10 (0.18%), Utilities 69 (1%). End Footnote.

Table 5:

The three most common categories of requests in 1997 were Housing 783 (15%), Vocational Rehabilitation 762 (15%), and Employment 556 (11%). Those were followed by Government Benefits 550 (11%), ADA, Abuse and Individual Rights 441 (9%), Health 409 (8%), Transportation 336 (7%), Personal Care and Independent Living 242 (5%) and Education 194 (4%). There were 746 (15%) Other requests. Footnote: For 1997, the Other Category includes Equipment 117 (2%), Insurance 21 (0.4%), Legal Assistance 168 (3%), Miscellaneous 357 (7%), Recreation 6 (0.001%), Taxes 19 (0.38%), Utilities 58 (1%). End Footnote.

Table 6:

The three most common categories of requests in 1998 were Housing 813 (14%), Vocational Rehabilitation 778 (14%), and Employment 764 (13%). Those were followed by Government Benefits 636 (11%), ADA, Abuse and Individual Rights 508 (9%), Transportation 390 (7%), Health 351 (6%), Personal Care and Independent Living 294 (5%) and Education 212 (4%). There were 988 (17%) Other requests. Footnote: For 1998, the Other Category includes Equipment 151 (3%), Insurance 69 (1%), Legal Assistance 317 (6%), Miscellaneous 380 (7%), Recreation 13 (0.22%), Taxes 16 (0.27%), Utilities 42 (0.73%). End Footnote.

Table 7:

The three most common categories of requests in 1999 were Housing 998 (15%), Vocational Rehabilitation 845 (13%), and Employment 846 (13%). Those were followed by Government Benefits 808 (12%), ADA, Abuse and Individual Rights 522 (8%), Health 429 (7%), Transportation 409 (6%), Personal Care and Independent Living 311 (5%) and Education 212 (3%). There were 1,172 (18%) Other requests.

Photo: Sybil Feldman enjoying accessible boating.

Examples of Client Services Cases

Case Number 1:

A social worker from a hospital in North Carolina called MOD attempting to locate a family member of a disabled man who had been brought to their facility after having a seizure on the street. He was experiencing some memory loss as a result of the seizure. He was able to remember that he lived in Boston, that he received social security, and that his sister was his representative payee, but he was not able to recall where she lived or how to reach her. In an attempt to identify his sister, the social worker had called approximately 30 agencies, including social security, the post office, and the police department. All calls proved futile. Traveler's Aid could not help him return to Boston unless someone would meet him there. The man had MOD's business card, and as a last resort, the social worker called the office. An advocate spoke with him and through a series of questions established the area and street where his sister lived. Directory Assistance provided a telephone number that MOD relayed to the social worker who was then able to contact his sister and arrange for him to return to Boston.

Photo: Max Ibanez and Christopher Coyle plan outreach visits to the Boston Living Center with Center representatives Chris Hall and Brian Welch.

Case Number 2:

Five employees of a government agency asked for assistance. Each has a severe visual impairment, resulting in their need for adaptive technology to operate computer equipment essential to doing their jobs. Their agency had just spent \$57 million on a new computer system, which was not compatible with available adaptive equipment. CSP brought together consumers, government, and private software providers. Within a few months, the accessibility issues had been resolved, the individuals trained and fully functional on their new computers. Without this effort, these individuals would have been unable to retain their jobs. This first-in-the-nation software package is now an award winning national model being used by several other states in the development of their computer systems.

Case Number 3:

A 53 year old woman with multiple disabilities had asked Vocational Rehabilitation (VR) to support her home based business goal of doing medical transcription and tee-shirt design. Because of the severity of her respiratory disability, she

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requested that she receive training at home. The whole plan was denied and the VR agency took action to close the case. An Administrative Review was requested because the case was denied. The Review found in favor of the consumer. Since that time the services she requested have been granted and she expected to be showing her tee shirts at several local trade shows during the holiday season.

Case Number 4:

A 32-year-old man with a learning disability was denied computer equipment and software that would enable him to function as a motion picture producer. His signed Individual Work Related Plan (IWRP) had contained this goal for several years and the Massachusetts Rehabilitation Commission (MRC) had provided tuition assistance for his completion of college and film school. Evidence presented at Administrative Review underscored the individual's inability to function effectively without computer assistance. The Review's decision was to authorize the requested equipment and to waive MRC's cap on technology expenses. The full cost of the equipment was covered and the man is now gainfully employed as a motion picture producer.

The majority of individuals who contact MOD with civil rights issues do so because they are unable to find pro bono lawyers until there is a finding by MCAD of Probable Cause. The civil rights advocate in the Client Assistance Unit assists clients in the informal and formal resolution of discrimination cases. The issues of concern brought to the civil rights advocate include credit, employment, education, housing, insurance, and public accommodations. If complaints can not be informally resolved, they may be filed with the Massachusetts Commission Against Discrimination (MCAD), the federal offices of Civil Rights, the Equal Employment Opportunity Commission, and the Department of Justice. Most are filed with MCAD. The advocate's responsibilities include filing, writing rebuttals, representation at investigative conferences, preliminary hearings, and conciliation.

Case Number 5:

A child who lived in a family public housing complex was raped by the child of another tenant. As a result, the child suffered Post Traumatic Stress and depression. She also had a Learning Disability. Her legal guardian, her grandmother, bought her a companion dog. The Housing Authority refused to let her keep the dog, and they did not investigate the alleged rape. A complaint was filed with the Massachusetts Commission Against Discrimination (MCAD). Probable Cause was found and the case was referred to the Attorney General's office for prosecution.

Case Number 6:

A man with cerebral palsy was denied a taxicab by 3 different taxis at South Station. One taxi driver claimed his cab was over-heated, one attempted to overcharge the man, and the other stated he could not take him because his taxi was not first in the taxi line. A Public Accommodations

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complaint was filed with the Massachusetts Commission Against Discrimination (MCAD). An investigative conference revealed that two of the drivers claimed the man looked drunk. Initially, MCAD found Lack of Probable Cause, stating that a reasonable person could believe the Complainant was drunk. The decision was appealed based on the fact that the individual's conversation was coherent and there was no alcohol on his breath. Affidavits from his former employer also stated that he did not drink on the job. It was also pointed out that if he had been drunk, he should have been taking a cab. The Commission vacated the Lack of Probable Cause, and replaced it with one of Probable Cause. As a result, two of the denials were resolved through conciliation and the third is awaiting a public hearing at MCAD.

GOVERNMENT SERVICES PROGRAM

The Government Services program ensures that Massachusetts' policies and practices are consistent with state and federal laws, and that the needs of people with disabilities are met. A mission of the Agency is to resolve problems before they turn into crises.

As a result of information gathered from the Client Service Program and the Community Services Program, MOD learns directly what is and what is not working for people with disabilities. This unit uses that information to "educate" other facets of government. The new Home Modification Program and reforms to the Personal Care Attendants Program are two such examples of its recent accomplishments.

Americans with Disabilities Act (ADA) State Compliance Efforts

MOD is also the designated agency for ensuring state compliance with the Americans with Disabilities Act (ADA). It is the touchstone within government for technical assistance, trouble shooting and advice on all disability related issues. All entities of state government are required to comply with the provisions of the Americans with Disabilities Act (ADA). Under the ADA, governments are required to make all their programs, activities and services accessible. This includes both physical access for people who have mobility impairments and communication

access for people with vision, hearing, and cognitive disabilities.

Inter-Agency Disability Services Coordinating Council and the Governor's Special Advisory Commission on Disability Policy

Through the Client Services Program and the Community Services Program, the Office on Disability knows first-hand the problems people with disabilities encounter as well as how government works. It works closely with state agencies and consumers to craft policy which is fair, effectively maximizes state dollars, and meets the needs of the community. Systemic planning and policy are integrated in the work of two bodies which are administered by MOD: the Inter-Agency Disability Services Coordinating Council,

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a body composed of heads of disability or disability-related agencies, and its consumer counterpart, the Governor's Special Advisory Commission on Disability Policy.

Inter-Agency Disability Services Coordinating Council

The Council was created by Executive Order 352 and has been meeting since late 1994. It is comprised of heads of agencies that provide disability or disability related services. The Council serves to:

- Improve the accessibility and delivery of services;
- Evaluate and monitor the system by which services are delivered and coordinate and develop recommendations for streamlining;
- Identify functions which would be more efficient if consolidated or eliminated;
- Make recommendations and report to the Governor from time to time; Coordinate with the Governor's Special Advisory Commission on Disability Policy.

Since its inception the Council's accomplishments include producing 3 reports on the disability service system including recommendations and findings. Each report represents a segment of services provided to people with disabilities in major age groups. A fourth report, an updated compilation of the 3 previously issued, was forwarded to the Governor and the Legislature in early 1999. Some of the general Findings and Recommendations contained in the report appear below.

Other Council activities include participating in a statewide regulation review process; work on reducing waiting lists; identifying and providing information on the particular needs and services of individuals with disabilities as they related to the development of a Medicaid managed care system; convening and co-sponsoring an Americans with Disabilities Act (ADA) Coalition that addressed ADA compliance in state government as well as access to state government.

Excerpts from, The Disability Service System: A Report on Existing Services, Barriers, Gaps and Duplications Footnote: Excerpts have been combined for presentation in this report. End Footnote.

GENERAL FINDINGS

1. The disability service system, in general, is fragmented; it requires transitions - frequently for children who are continually aging out of systems - and is disruptive to families and consumers. In all cases, fragmentation is due to the fact that the system is driven by separate funding streams, different eligibility criteria and agency focus rather than individual need. For example, a child with special health care needs might enter the system through Medicaid, the reimbursement agency; her case would be managed by the Department of Public Health (DPH) and actual services would be provided by a contracting agency in the community. If she is in the Early Intervention Program (the primary program that provides services for children from birth through age 2 with disabilities, or children who are at risk, biologically or environmentally, of

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development delay) she ages out when she turns 3. Her family is then faced with entering another system (preschool, if eligible, or day care, if affordable) until that child is 5; she then leaves that system to enter school.

2. Case management services are duplicated from agency to agency. This results in inefficiencies which are neither cost effective nor beneficial to consumers. At the same time, funding constraints and high caseloads also limit this service. This may have the result of providing less effective and, in the long run, more costly care for consumers who would benefit from a coordinated service plan.

3. Eligibility criteria preclude some consumers from receiving services either because of gaps between services for which an individual is eligible (this is apparent in criteria based on age), or because some consumers with less common disability diagnoses or with complex service needs that do not meet specific criteria.

4. No accurate numbers exist on the unmet need for services. Waiting lists only identify those people who are in the system, and current projections of the unmet needs are extrapolations based on national disability prevalence rates.

5. Transportation services are essential to people with disabilities who live in the community or in facilities such as nursing homes. These services are defined by their funding source, or they may be tied to programs with which agencies have contracts. This results in a system that is piece-meal, uncoordinated, and in some cases, duplicated. Individuals with disabilities also rely heavily on public transportation. Some metropolitan areas in the Commonwealth have vast public transportation systems which frequently do not meet the accessibility standards mandated in the Americans with Disabilities Act (ADA) and other laws. In contrast, rural transportation services are both inadequate and extremely limited, if they exist at all. In addition, the Regional Transit Authorities (RTAs) must contend with an expanding customer base – the result of an aging population, federal laws, and lack of full accessibility in public transportation systems – and a lack of new dollars to meet this growth.

6. Information and Referral (I&R) systems, as the linchpin of disability services, are fragmented and limited, thus creating barriers to services for consumers whose needs go beyond the immediate agency through which they entered the system. Existing systems are not multilingual

and as such impede access for individuals for whom English is not the primary language.

7. Protective services and abuse investigations exist within five state agencies (e.g. DPPC, DMR, DPH, MRC, and DMH), all but one of which provide services for people with disabilities. Services are duplicated, lack uniformity, and are too narrowly restricted by the statutory definition of “abuse” that is limited to that perpetrated by a caretaker.

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RECOMMENDATIONS

1. To minimize systemic fragmentation and frequent transitions:

- Remove rigid category definitions
- Utilize inter-agency service agreements
- Implement appropriate legislative and regulatory changes
- Seek federal waivers
- Increase outreach and education to consumers at “transitions” and when systems and procedures change to avoid confusion and frustration, interruption and termination of services

2. To preclude duplication of case management services when dual or multi agency services are required, delegate responsibility for an individual client to a lead case manager and define agency links. In some cases, a co-case manager may be appropriate to provide assistance to the lead agency regarding technical assistance in a specialty area. In most other cases, when more than one agency is involved, the services of each should be defined in a service plan and should be complementary.

3. Develop a strategy around “gap” consumers who are not receiving vital services due to eligibility criteria. Consider allocating funds to non-service providing agencies that have expertise in those disabilities.

4. Develop a strategy to fund outreach efforts that aim to inform individuals who need services but are not in the system, about available services and how to access them.

5. To improve efficiencies, cost effectiveness, and user friendliness in the public transportation system:

- **eliminate eligibility criteria for receiving public transportation services between the systems which serve the elderly and individuals with disabilities,**
- **coordinate funding streams, transportation routes, and schedules,**
- **increase outreach and training in accessing and using existing rural transportation services,**
- **establish a task force to study the cost effectiveness, and impact on consumers, of eliminating the brokerage system currently utilized by the Regional Transit Authorities (RTAs), and to identify potential revenue sources for expanding fixed route service which is currently limited, and transportation in rural communities.**

6. Expand the existing disability Information and Referral Program in the Massachusetts Office on Disability (MOD) to provide a broad range of information through a single source, which is

available to all people with disabilities, agencies, and individuals outside the system. This program is already accessible statewide through an 800 number and by TDD (telecommunication device for the deaf). It also provides cross-disability information.

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7. Consolidate abuse investigations into a single, independent agency and expand its jurisdiction to include neglect and abuse by individuals other than caretakers, financial exploitation, and people with disabilities 60 years of age and older who are living in DMH and DMR funded facilities. Provide adequate resources to cover the expanded legal and practical capacity including forensic experts.

Photo: Members of Governor's Advisory Committee on Disability with MOD staff and then Lt. Governor Cellucci

Governor's Special Advisory Commission on Disability Policy The Commission was created by Executive Order 351, and has been meeting since 1994. It is comprised of consumers and family members with direct experience and expertise in the disability service system. It represents a cross-disability constituency as well as all major geographic areas in the Commonwealth. The Commission acts to:

Establish a formal mechanism through which people with disabilities lend their input, experience and advice to the Governor on the development and implementation of public policy, Provide guidance, from a consumer perspective, on the design and delivery of services and assistance to people with disabilities, Coordinate with the Inter-Agency Disability Services Coordinating Council.

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Photo: Leo Lucas boards a fixed route bus.

Highlights of the Commission's accomplishments include: a leading role in a successful initiative to bring about major reforms in the Personal Care Attendant (PCA) Program; working at the grass roots level with Community Access Monitors to make communities accessible and to bring about awareness of disability issues; and, coordinating with the Inter-Agency Disability Services Coordinating Council in designing effective policy recommendations.

VI PUBLICATIONS

Financial Programs/Technical Assistance for Local Governments and Funding Sources for Home Modifications, January 1998

Disability Laws in Massachusetts, March 1999

The Disability Service System, A Report on Existing Services, Barriers, Gaps and Duplications, April 1998

VII SIGNIFICANT ACCOMPLISHMENTS

Community Access Monitor (CAM) Program

The CAM Project was created in 1986. Since then approximately 10,000 people have been trained by the Massachusetts Office on Disability to survey buildings for accessibility and to advocate for compliance. More than 1,200 people have been certified as Community Access Monitors.

Initially, the Community Access Monitor Project emphasized the enforcement of the Architectural Access Board's rules and regulations. Now, with the federal Americans with Disabilities Act in effect, requirement for access has broadened to include communication and programmatic as well as architectural accessibility. As the scope of accessibility legislation has broadened, so has the role of the Community Access Monitor.

Accessibility

Architectural, communication, programmatic, and policy barriers prevent people from participating fully in society. People with disabilities cannot assume they can use common public places such as stores, banks, offices, and restaurants, or participate in ordinary activities such as working, getting an education, visiting friends, and attending community and cultural events. Most non-disabled individuals take these freedoms for granted.

Accessibility means much more than ramps for wheelchair access. People with all types of physical, sensory, cognitive and other disabilities must be ensured equal access to facilities, services, and programs. Structural barriers, unequal policies and practices, or inaccessible means of communication and dissemination of information are discriminatory against people with disabilities.

Photo: Myra Berloff receives her Carballo Award from Governor Cellucci.

Photo: Christopher Coyle receives his Carballo Award from Governor Cellucci and Secretary of Administration and Finance Natsios.

The Role of the Community Access Monitor

Community Access Monitors play an essential role in encouraging access improvements. While they do not have legal enforcement authority, monitors have proven to be highly effective advocates. Monitors are a full partner in the implementation process by coordinating advocacy efforts with municipal disability commissions, Independent Living Centers, ADA Coordinators, building inspectors, and others.

Being a Community Access Monitor requires knowledge of access laws and regulations, understanding of the range of organizations that have responsibilities under both state and federal regulations, skill in surveying and advocacy, and the ability to be persuasive and persistent.

Department of Justice Conference

In May 1996, MOD won a competitive grant from the Department of Justice for an ADA conference. The conference, ADA WITHOUT FEAR: solutions for state and local government, was held to a sell-out audience. The Commonwealth's commitment to fulfilling the Americans with Disabilities Act, had been slowed by economic constraints. The goal of the conference was to bring about successful compliance with the ADA by establishing a network to provide both information and resources and to link ADA decision makers in state and local government. The conference also promoted awareness about how to access available educational and technical assistance resources on the ADA at the federal, state, and local level.

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Personal Care Attendant Reforms

The Office on Disability played a critical role in bringing about major reforms in the Personal Care Attendant (PCA) Program, which is administered by the Division of Medical Assistance (Medicaid). Personal care attendants provide services such as assistance in getting out of bed, dressing, bathing, and other similar activities, to people who are deemed to be at risk of institutionalization. In 1997, MOD, working with the Division of Medical Assistance, the Statewide Independent Living Council, and the Governor's Advisory Commission on Disability Policy, forged a Memo of Understanding which started the reform process. The fundamental tenet of the program, consumer control, was preserved, and reform initiatives resolved tax, unemployment, and worker compensation issues. A pay increase was also included. The new PCA program was implemented in early 1999.

Photo: Brad Pearson receives his Carballo Award from Governor Cellucci

Manuel Carballo Award for Excellence in Public Service

MOD has been honored for three consecutive years by a staff member receiving the Manuel Carballo Award for Excellence in Public Service. Each year the Commonwealth bestows this prestigious honor on ten outstanding public servants. Christopher Coyle, an Advocate in the Client Services Unit, received this award in 1999. Brad Pearson, an Advocate in the Client Assistance Program, was a recipient in 1998, and in 1997, Myra Berloff, Assistant Director of Community Services, was chosen. This is the highest honor a public employee can receive.

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